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The Impact of Physical and Social Characteristics
of Cerebral Palsy on the Utilization
of Day Program Services

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Donaciano O. Meza

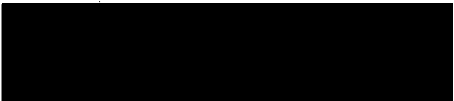
June 1995

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6-6-95
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Abstract

This study examined the characteristics of cerebral palsy that affect the utilization of day program services. The study will provide a base for further explanation in this area as it gives clarity to the question of whether characteristics of cerebral palsy have an affect on the utilization of day program services. The literature supports the need for normalization and integration of disabled individuals in the community and the work place.

The study found that there is significance in the relationship between the use of day program services and the level of retardation of the client, their place of residence, their primary language, and the ability to express themselves. The level and location of motor dysfunction caused by the cerebral palsy, the ambulatory skills, the toileting skills, and the social behaviors of the client were not found to have a significant relationship.

This study could impact social workers on direct practice and administrative levels as the focus from more traditional modes changes.

Table of Contents

Abstract.	iii
Tables	vi
Figures	vii
 Chapter One	 1
Introduction	1
Problem Statement.	2
Problem Focus	3
Chapter Two	7
Literature Review	7
Introduction to Regional Center	7
Self-Concept and Physical Impairment	8
Supports and Services	10
Chapter Three	15
Methods	15
Purpose of Study	15
Research Question and Hypothesis	15
Sampling	16
Data Collection and Instruments	17
Procedure	19
Protection of Human Subjects	20
Chapter Four	
Results	21

Analysis	21
Demographics	22
Day Program Participation by Physical and Social Characteristics	24
Other Relationships	31
Chapter Five	34
Discussion	34
Conclusions	34
Recommendations and Implications for Practice. .	39
Implications for Research	41
Appendix A:Title	43
Data Abstraction Form.	44
References	46

List of Tables

Table

1.	Comparison of Demographics Based on Day Program Participation	23
2.	Comparison of Day Program Participation by Level of Retardation	25
3.	Comparison of Day Program Participation by Place of Residence	27
4.	Comparison of Day Program Participation by Primary Language	28
5.	Comparison of Day Program Participation by Gender	29
6.	Comparison of Day Program Participation by Physical and Social Characteristics of Cerebral Palsy	31

Figures

Figure

1. Comparisons of Place of Residence, Primary Language, and Retardation for Clients with Cerebral Palsy 32

Chapter 1

Introduction

There are many individuals who are born with developmental disabilities. These individuals have special care needs and are often considered burdens on their families and community. Developmental disabilities can limit individuals in the way that they are able to function in their communities. Different disabilities impose different limitations on individuals. The different types of developmental disabilities include: mental retardation, epilepsy, autism, and cerebral palsy. Of these, cerebral palsy has the most obvious physical effect on individuals.

Persons afflicted with a developmental disability experience unique challenges throughout their lives and usually require the assistance of their families as well as available community resources. Families can be supportive but often encounter emotional difficulties in accepting their child's disability. The families may experience denial, loss, grief, and "burn-out" caring for a severely disabled child (Blumberg 1975). The Americans with Disabilities Act (ADA) of 1990 prohibits the discrimination of disabled persons in employment, participation in state or local services, public accommodations and in telecommunications (Orlin 1995). The act was designed to

provide the disabled person with the opportunities offered to the non-disabled of the community. The community has services to offer the disabled but these are limited in number, and often not visible to the non-disabled population.

Regional Centers were organized in the State of California in the early 1970's to develop and improve access to community resources for the developmentally disabled. The Regional Center functions as a type of "broker" of resources in the community. The Regional Centers also provide direct services to educate the public toward the prevention of developmental disabilities.

Problem Statement

As a disability, cerebral palsy is a challenge to the person who is afflicted.

Cerebral palsy is an inclusive term of a variety of nonprogressive disorders, resulting from brain damage, of motor function in young children. Damage to the brain can occur before, during, or shortly after birth and may be caused by a number of different circumstances. Prenatal causes or factors include developmental defects, inherited metabolic errors, maternal infections such as rubella, irradiation, asphyxia, administration of harmful drugs to the mother, and toxemia of pregnancy. The natal factors include trauma in delivery; anoxia, or oxygen deficiency; and prematurity. In the postnatal period the injurious factors include trauma, anoxia, infections, cerebral vascular lesions, and Rh incompatibility.

The symptoms and signs of cerebral palsy depend upon the distribution and severity of changes in the brain. On this basis, five groups are recognized: (1) spastic diplegia, with exaggeration of voluntary movements; (2) hemiplegic cerebral palsy, with half of the body affected; (3) spastic

quadriplegia, with choreoathetosis, or uncontrollable movement; (4) athetotic cerebral palsy, with uncontrolled movements of the affected muscles; and (5) ataxic cerebral palsy, in which balance is disturbed. These categories commonly overlap because of multiple symptoms. Moreover, defects in vision and speech and convulsive seizures may be present. About 30 percent or more of children having cerebral palsy are mentally retarded (Funk & Wagnalls, 1986).

This disability limits a person's chances for independence by affecting their ability to communicate and get around. These limitations affect the person's ability to function in the community in employment opportunities and living situations. The severity of cerebral palsy in the individual will have a great effect on what services are available to the person in the community. In some cases of cerebral palsy, the individual can be of average or above average intelligence, have goals of higher education and a career, only to be restricted by a body that will not cooperate.

The disability of cerebral palsy can be both physically and intellectually limiting. The person afflicted with this disability will experience challenges in obtaining employment, housing, transportation, and appropriate medical services in the community.

Problem Focus

This study examined the characteristics of cerebral palsy that affect the utilization of day program services by

adults with cerebral palsy who are clients of Inland Regional Center. The study provides a base for further study in this area as it gives clarity to the question of whether characteristics of cerebral palsy have an affect on the utilization of day program services.

This study looked at the relationship that exists between the severity of the disability, and the availability of an appropriate day program (school, work, or social/recreational activity) for individuals with cerebral palsy.

There are a variety of day programs that are available in the community. Some day programs, such as Goodwill Industries, serve the disabled population by offering a "sheltered" environment as a part of their design. Goodwill Industries also employs the use of community based enclaves in the community. These enclaves usually provide services at community based "fast food" restaurants, on lawn crews, or highway rest stops. They usually consist of 4-6 clients and a job coach. The variety of work depends on the creativity of the job developer. Some lesser known programs, such as the Association for Retarded Citizens, provide daily activities and developmental opportunities for a focus on integration with the non-disabled.

The more severe the physical limitations are, regardless of intellectual functioning, the more limited the resources will be. Because these various services exist

separately in communities, it is essential for professional health staff working in communities to become very familiar with them, so that disabled individuals may be referred promptly for diagnosis, treatment, habilitation, and care.

The positivist paradigm was used to research the characteristics of cerebral palsy which affect utilization of day program services. This was an exploratory study that examined how characteristics of cerebral palsy such as intellectual and physical abilities affect utilization of day program services. There are currently community based day programs that serve individuals with cerebral palsy. There are, however, individuals with cerebral palsy that do not participate in them.

This research is necessary in exploring the needs of the community from an administrative point of view. Program development relies on research and statistics in better meeting the needs of the community. Public support is important in this goal, and the research allows for clarity in the description of the needs of individuals with cerebral palsy. This research will be valuable to agencies that serve the disabled by providing data which will help in future resource development and delivery. It will benefit the agencies by identifying areas where service and program development and improvement are needed.

The social worker should have knowledge of what is available in the community in order to better serve the client. It is the responsibility of the administration to gather information that they can provide to their social workers to meet the needs of their clients. The ultimate goal of the research is to encourage program development, provide more normalization, integration, and inclusion opportunities; and to improve community awareness and collaboration between the disabled and their communities.

Chapter 2

Literature Review

Introduction to Regional Center

Normalization, integration, and inclusion are goals of the Regional Center in developing and providing services for the developmentally disabled. Integration of disabled persons in community employment, recreational, and educational environments benefit both the disabled and the community. Inclusion of disabled persons in non-disabled activities broaden the awareness of the community and the community benefits from the contributions of the disabled person.

Normalization is the primary goal of the Regional Centers. The Department of Developmental Services, in its long range plan for 1990-1995 encourages,

"community-based day programs to select community integration as their primary curriculum objective when implementing the new regulations for nonresidential services; develop innovative ways of delivering this curriculum; and evaluate the effectiveness of the new regulations in promoting community integration" (California 1990).

The Regional Centers help to provide opportunities for the developmentally disabled that allow them to participate in activities already appreciated by the non-disabled.

The Regional Center is an organization that was created to act as a liaison for resources in the community and to

develop new resources. Through the Regional Center clients receive a diagnosis that makes them eligible for services. Advocacy and service provision for the developmentally disabled population was a major part of the creation of regional centers.

Agency philosophy supports the need for normalization services, the physical limitations and implications of cerebral palsy, as well as the responsibility of the community of providing services through the Americans with Disabilities Act (ADA) of 1990. The search of formal academic literature revealed a limited number of related articles to the specific research question. There were no articles found related to the utilization of day program services by clients with cerebral palsy. There was, however, related research that gives support to the research question.

Self-Concept and Physical Impairment

The concept of normalization and integration are important to this research study. They are the focus for broader opportunities for individuals with disabilities. Lubin, Jacobson, and Kiely, in their 1982 study found that for those with mild physical impairment, inclusion varies as a function of categorical disability, age, and level of

intellectual functioning (Lubin 1982). Within the disabled community there are individuals that are kept from being successful in a non-disabled world due to their physical limitations. Lubin, Jacobson, and Kiely make reference to a hierarchy of abilities as well as prejudices within the community from which the disabled are judged by the non-disabled. The functional abilities of the clients affect their access to services in the community. Other factors such as learned helplessness can be limiting factors to continued client success in independent living.

Basil, in her 1992 study, investigated the learned helplessness of children with disabilities that they carried on into adulthood. This study showed that interactive techniques taught to the families and children helped in future learning and development of conversational patterns (Basil 1992). The ability to express an idea or a feeling can be difficult and frustrating for a person with cerebral palsy. A study in 1973 by McDonald showed that the level of frustration and resulting behavior problems can be alleviated through the use of communication boards. His study illustrates that considerable improvement in linguistic skills occurs when such individuals are able to express their thoughts and feelings (McDonald 1973). The ability to communicate is often taken for granted and poor

communication skills can be misinterpreted as mental retardation or a more severe condition.

Magill-Evans in her 1991 study, measured the self-esteem in disabled and non-disabled adults and found that women with cerebral palsy tended to have more difficulty with self-esteem when younger but showed no difference as adults when compared to non-disabled females. Men with cerebral palsy were found to have similar results to the non-disabled males studied (Magill-Evans 1991). In a 1983 study it was found that disabled Russian adolescents, although scoring similarly to non-disabled peers on self-esteem tests, were found to have a low level of ego evaluation overall (Romanova 1983). Through support from parents and generic community resources individuals with cerebral palsy can function better in the community. The literature shows that the disabled are not much different in their expectations of life. It is therefore plausible that with some assistance, clients can become more confident in pursuing independence.

Supports and Services

Research in areas such as program models, residential supports, and obstacles to employment integration contribute to the understanding of the challenge to inclusion for the

person with cerebral palsy. In a study by Stelk and Richards they described the use of paraprofessionals called mentors. These mentors were members of an Interdisciplinary Team that assisted individuals with profound and severe disabilities in living in individualized residential situations (Stelk 1992). This type of assistance can be the difference between success and failure in community oriented day programs. This type of independent living can allow over-protective parents the opportunity to take a controlled risk in allowing their children to emancipate themselves from the parental home. The self-esteem of the client and the support of those around them are important factors.

Mason in his 1989 dissertation studied how a horseback riding program helped to improve self-concept in individuals with cerebral palsy (Mason 1989). The opportunity to socialize with others, and to participate as a team in learning to ride a horse helped improve self-concept and improve confidence. This type of program is beneficial to the client in that it gets them out into the community, and allows for integration between the disabled and the non-disabled. The problem that exists with such a program is in quantifying the progress made by horseback riding. Fox, in her 1984 study, developed a test instrument to objectively quantify the progress of 19 teenagers with cerebral palsy participating in horseback riding. The clinical impressions

of the therapists and parents suggested progress in characteristics such as self-confidence and interaction with others (Fox 1984). Her results supported the use of the test instrument. The use of such programs can be expensive, however, and it is difficult to justify continued use when other community supports can be utilized in developing self-esteem for the disabled person.

The road to independent functioning is not an easy one and often there are problems associated with success. Knishkowsky and others, in their 1986 work, discuss patient care and resident training in a residential facility. They focused on problems often associated with cerebral palsy and program objectives for helping clients achieve independent functioning in the community (Knishkowsky 1986). Janicki in his 1982 study of New York, found that the majority of developmentally disabled persons resided in the community rather than in state institutions. The Coffelt Agreement of 1994 in the state of California provides for 21 Regional Centers to share the task of placing, into the community, developmentally disabled clients currently in the State Developmental Centers. Over a five year period, the regional centers will be expected to appropriately place 2000 clients. The state will provide additional funding to the regional centers to develop community resources

appropriate to improve the chances of achieving successful community placements.

Alexander, in his 1990 book outlines the difficulties in transitioning a person with cerebral palsy into independent and autonomous living (Alexander 1990). He describes the difficulty in screening out candidates and anticipating for educational and behavioral issues. He suggests that the disabled be assessed for skills in order to have more successful candidates. It is this researcher's belief, however, that the ultimate goal is not to "cream" the best candidates. Rather, emphasis in research and practice should be to provide opportunities so that all disabled individuals can benefit equally from available programs.

There will be obstacles in the way of achieving independent and autonomous living. These obstacles may come in the form of legislation limiting certain opportunities, a lack of funds, or uncooperative community officials. Jonas, in his 1981 work discusses, conceptually and philosophically, the needs of cerebral palsied individuals and their families in terms of legislation affecting housing, education, and employment (Jonas 1981). With the recent passage of the ADA, individuals with disabilities will have more opportunities than ever to fair housing, education, and employment.

The opportunity of employment for equal pay among the non-disabled, will depend upon the physical abilities of the client, and the willingness of the employer to accommodate the disabled employee. Barney, in his 1974 work examined age, education, and work experience as being factors which affect a positive rehabilitative outcome (Barney 1974). However, he chose to exclude persons with mental retardation, hemiplegia, or severe cerebral palsy. This type of exclusion has limited the progress of the disabled in competitive employment. Through the ADA, individuals with disabilities will have more opportunities than ever to be competitively employed as well as to have equal access to public facilities in their own communities.

There is a need for continued study in these areas since currently there are gaps in the literature. The current trend toward normalization, and the studies that stem from it, will help to fill these gaps such as in Barney's 1974 work.

Chapter 3

Methods

Purpose of the Study

The purpose of this study was to explore the utilization of day program services by individuals afflicted with cerebral palsy. The characteristics of cerebral palsy differ with the individual and pose unique barriers that may be limiting to the person. The characteristics of cerebral palsy were compared in their effects on the individual's ability to integrate with the community.

The study takes the positivist perspective as it explores utilization of day program services through existing case record data at the Inland Regional Center, in Southern California. The data was used to identify trends or correlations related to the utilization of day program services.

Research Question and Hypothesis

The research question studied was the following: What physical and behavioral characteristics of cerebral palsy affect procurement of appropriate day program services?

The hypothesis predicts the existence of a direct relationship between the severity of affliction of the cerebral palsied client and the availability of appropriate

day program services. The characteristics of cerebral palsy of each client will keep the client from participating in a day program.

Sampling

The sampling frame consisted of all clients age 18-67 served by Inland Regional Center with a diagnosis of cerebral palsy. In order to obtain a random sample, a complete list of Unique Client identifier (UCI) numbers for this group was obtained with the assistance of the main regional center computer. The UCI number is a seven digit computer number generated for each regional center to represent each of its clients, and is encoded on each of the client's "Client Development Evaluation Reports" (CDER). It allows for data analysis while safeguarding the confidentiality of client data (California 1986a).

The sample was obtained from the Inland Regional Center's directory of clients. The regional center currently serves approximately 11,000 developmentally disabled clients. The regional center computer generated a list of 2802 clients that have cerebral palsy as one of their diagnoses of eligibility; clients may have multiple diagnoses such as cerebral palsy accompanied by mental retardation. A sample of 200 clients was taken, by sampling

every fourteenth client from the total population of clients with cerebral palsy. A sample of 200 cases was used in order maximize bivariate data analyses.

Data Collection and Instruments

The data was collected from preexisting CDERs with permission from the Inland Regional Center.

The Client Development Evaluation Report (CDER) is an assessment instrument which collects information about a client's developmental status, their demographic characteristics, and their service patterns. It was originally implemented by the Department of Developmental Services and the Regional Centers in 1979 at which time all active clients were assessed. Currently, the CDER is completed when a client is first determined to be eligible for regional center services at intake, when a client is transferred from one regional center to another, or annually at the time of the annual review of the client. It may also be updated as needed as when a significant life or situation change has occurred.

The CDER is generally completed by an Interdisciplinary Team (IDT), which consists minimally of the client and the case manager/social worker from the regional center. Other members of the IDT may include the primary care provider,

family members, school or day program representatives, or any significant other who might have relevant input.

The CDER is considered a valid and highly reliable instrument (California 1986a). When processed by computer, the CDER yields two products. One, the "Summary Turnaround" lists data in a numerical form, while the other, the "Client Profile" translates the data into written English. In analyzing data for this study both products were used. The summary turnaround for analysis purposes, and the client profile to correlate digital information with an analog description.

The strength of this data collection method is found in its' richness of information. It supplies a great deal of demographic, psycho-social, medical, motor skill, and behavioral information on the client. The information is updated at least on a yearly basis and was sufficiently current for the purpose of this study. The critical information is in numerical form and is deciphered with a CDER manual.

A weakness of the CDER is seen in how it is updated. The updates, usually annually, are the responsibility of the case manager in charge of the case. The entries can be subjective and reflect the case managers views and experiences. The CDER is a valid instrument, but relies on

consistency and a standardized approach when updating the data.

Procedure

Once the CDER profiles were obtained from the computer operator, numerical data was gathered directly from the CDER document. The data was deciphered by using a data abstraction form. The data abstraction form utilized the numerical equivalents from the CDER for each of the variables used. The numerical equivalents used are each defined by the CDER manual. These numerical equivalents were used in computing for correlation and strength between the variables. A copy of the data abstraction used may be found in the appendix at the end of this project.

The variables are as follows: gender, age, ethnicity, primary language, expressive skills, ambulatory skills, toileting skills, level of motor dysfunction, location of motor dysfunction, retardation level, medical conditions, medical conditions impact, day program, social behavior, and residence type. These variables are representative of physical and behavioral characteristics of the cerebral palsied client that affect daily living. These variables are believed to influence the opportunities a person with cerebral palsy has in attending a day program.

Protection of Human Subjects

The confidentiality of human subjects was protected by destroying CDER profiles and data abstraction forms at the completion of the research. Client names were not used in this study. There were no clients under the age of 18 used in this study. All information was gathered from existing client files, and the CDER document.

Chapter 4

Results

Analysis

The dependent variable for the purpose of this study was day program utilization. The independent variables were those physical and behavioral characteristics of the cerebral palsied individual that affect participation in a day program. This research study used quantatative analysis to examine the strength of the relationship between the dependent and independent variables. The variables used in this research study were primarily of the nominal or ordinal type.

The "EPI Info 6", statistical computer program was used for the purpose of data entry as well as for analysis of the data. The only interval variable used was "age". The following nominal variables were used: gender, ethnicity, primary language, chronic medical conditions, level of motor dysfunction, location of motor dysfunction, day program, and residence type. The following ordinal level variables were used: ambulatory skills, toileting skills, expressive skills, retardation level, medical conditions impact, and social behavior. The data was collected and used to compare clients who were involved in some type of a day program and those who were not. The data abstraction form in the

appendix of this paper will clarify how each of these variables was broken down in terms of their ordinal and nominal values.

The EPI program was used to run frequency tables to examine the data for measures of central tendency. Frequency tables were run for age, gender, ethnicity, primary language, and place of residence as they related to participation in a day program.

Chi-Square tabulations were run in order to find a relationship between day program participation and the following variables: level of retardation, place of residence, primary language, level of motor dysfunction, location of motor dysfunction, age, gender, chronic medical conditions, medical conditions impact, ambulatory skills, toileting skills and expressive language. Additionally, a cross-tabulation was run to assess the relationship between residence, primary language, and level of retardation.

Demographics

Demographics of 200 clients with cerebral palsy broke down in the following manner. The ages of the sample ranged from 18-67 years, with a mean of 34 as shown in table 1. The median was 33, and the modal age slightly lower at 24.

Table 1. Comparison of Demographics Based on Day Program Participation

Variables	Day Prog. ^a (N=150)		No Day Prog. ^b (N=50)		Total ^c (N=200)	
	n	%	n	%	n	%
Gender						
Female	64	43.0	31	62.0	95	47.0
Male	86	57.0	19	38.0	105	53.0
Ethnicity						
Mixed	5	3.0	4	8.0	9	4.0
African Amer.	11	7.0	2	4.0	13	7.0
Spanish/Latin	26	17.0	14	28.0	40	20.0
Caucasion	104	70.0	30	60.0	134	67.0
Other	4	3.0	0	-	4	2.0
Primary Language						
English	143	95.0	42	84.0	185	93.0
Spanish	6	4.0	7	14.0	13	6.0
Other	1	1.0	1	2.0	2	1.0
Residence Type						
Home	64	43.0	28	56.0	92	46.0
Community Care	86	57.0	22	44.0	108	54.0

^aMean age of the clients who participated in a day program = 33.727, Standard Deviation = 10.51.

^bMean age of the clients who did not participate in a day program = 36.40, Standard Deviation = 11.90.

^cMean age of the total clients = 34.40, Standard Deviation = 10.904.

The sample was almost evenly split in gender 47(95) percent female, and 53(105) percent male. The ethnic breakdown of the group was: 67(134) percent Caucasian, 20(40) percent Hispanic, 7(13) percent African American, 4(9) percent of mixed background, and 2(4) percent were a mix from the remaining ethnic groups. The primary language of the group was English, with 93(185) percent. Six (13) percent of the individuals spoke only Spanish, and 1(2) percent considered missing data. Of the sample 46(92) percent resided independently or with family, the other 54(108) percent resided in some type of community based residence ranging from board and care to a state developmental center placement.

Day Program Participation by Physical and Social Characteristics

There were four characteristics that significantly affected the utilization of day programs by adults with cerebral palsy. They are: level of mental retardation, place of residence, primary language and gender.

Table 2 shows the relationship between participation in a day program and retardation level. Essentially individuals with cerebral palsy and moderate to profound

Table 2. Comparison of Day Program Participation by Level of Retardation

	<u>Day Program Attendance</u>		<u>Total</u>
	Attended	Did Not	
<u>Retardation</u>			
Affected	100 67.0%	23 46.0%	123 (62%)
Unaffected	50 33.0%	27 54.0%	77 (38%)
Total	150 100.0%	50 100.0%	200

Chi Square = 5.92
P-value = 0.015

mental retardation are more apt to attend day programs than those who are mildly or not mentally retarded at all.

The chi square analysis indicates that there exists a significant relationship between the level of retardation and day program participation. The Yates corrected p-value of significance for this chi square was 0.015. It should be noted that the data was re-coded in order to keep within chi square norms. The level of retardation was re-coded by combining the moderate, profound, and severely mentally retarded individuals into one group. The mildly retarded and the unaffected were placed into a second group. The group was re-coded in this fashion because the moderate to profoundly retarded individuals, typically, are limited by

their mental capacity while the mildly and non-retarded are usually not affected. The day program variable remained unaffected with two groups, one of clients attending, the other of clients not attending. This chi-square indicated that 67 percent of individuals considered affected by retardation attended a day program, while only 33 percent of those unaffected attended.

Adults who have cerebral palsy and live in a board and care are more apt to attend a day program than those who live at home with relatives or independently. Table 3 shows the relationship between participation in a day program and place of residence. There was significance in the relationship between place of residence, and day program participation as well. The residence variable was re-coded to keep within chi square norms. The residence variables were divided into the four basic residence types: board and care facility, developmental center, intermediate care facility, and own home. The Yates corrected p-value for this chi square table was 0.0003, which indicated a strong relationship between the place of residence and day program participation. As an example, 92 percent of the clients residing in a board and care participated in a day program; only 8 percent did not attend. Similarly 79 percent in intermediate nursing care were in day programs. This is

Table 3. Comparison of Day Program Participation by Place of Residence

	<u>Day Program Attendance</u>		<u>Total</u>
	Attended	Did Not	
<u>Residence</u>			
Board and Care	35 <u>92.0%</u> 23.0%	3 8.0% 6.0%	38 (19%)
Developmental Center	2 25.0% 1.0%	6 75.0% 12.0%	8 (4%)
Intermediate/ Nursing Care	49 <u>79.0%</u> 33.0%	13 21.0% 26.0%	62 (31%)
Relative/ Own Home	64 70.0% 43.0%	28 30.0% 56.0%	92 (46%)
Total	150 100.0%	50 100.0%	200

Chi Square = 18.58
P-value = 0.000

in contrast to the 70 percent of those living at home who attended day programs. The clients living in developmental centers made up the largest percentage of clients not attending a group of any of the categories of residence at 12 percent. This is due, in part, to the nature of the developmental center where clients tend to be isolated from

the community. The day programs available to these clients, consist of internal programs rather than programs based in the community.

Adults who have cerebral palsy and speak English as their primary language are more apt to attend day programs than those who only speak Spanish. Table 4 shows the relationship between participation in a day program and primary language.

Table 4. Comparison of Day Program Participation by Primary Language

	<u>Day Program Attendance</u>		<u>Total</u>
	Attended	Did Not	
<u>Primary Lang.</u>			
English	144 77.0% 96.0%	43 23.0% 86.0%	187 (94%)
Spanish	6 46.0% 4.0%	7 54.0% 14.0%	13 (6%)
Total	150 100.0%	50 100.0%	200

Chi Square = 4.63
P-value = 0.031

There was significance indicated between primary language and day program participation. Since the majority of clients were either in the English, or Spanish speaking only group, the variable was re-coded in this fashion in order to keep within chi square norms. The Yates corrected p-value was 0.031. This table indicated that 77(144) percent of individuals that speak English attend day programs, while 54(7) percent of Spanish speaking only clients were not attending a day program.

There was significance indicated in the analysis in the relationship between males and females attending. Table 5

Table 5. Comparison of Day Program Participation by Gender

	<u>Day Program Attendance</u>		<u>Total</u>
	Attended	Did Not	
<u>Gender</u>			
Female	64 67.0% 43.0%	31 33.0% 62.0%	95 (47%)
Male	86 82.0% 57.0%	19 18.0% 38.0%	105 (53%)
Total	150 100.0%	50 100.0%	200

Chi Square = 4.87
P-value = 0.027

shows the relationship between participation in a day program and the gender of the client. Essentially, males with cerebral palsy were more apt to attend day programs than were the female clients. The Yates corrected p-value of significance for this table was 0.027. The table indicated that the majority of males, 82(86) percent were attending, when only 67(64) percent of the females were attending.

Other physical and social characteristics were tested for their effects on client participation in day programs. Tested was the hypothesis that characteristics such as motor dysfunction and social behavior would affect day program participation. As indicated by Table 6, these characteristics were not found to be significant to day program participation. Additional chi square tables were run to explore any relationships between the remaining independent variables, however, these showed no significant relationships. The variables used in these tables were: age, level of motor dysfunction, bodily location of the motor dysfunction, chronic medical conditions, impact of chronic medical conditions, social behavior, ambulatory skills, and toileting skills. These variables showed no significant relationship with day program participation.

Table 6. Comparison of Day Program Participation by Physical and Social Characteristics of Cerebral Palsy

Variable	Chi-Square	p-Value
Age ^a	0.06	0.804
Chronic Medical Condition ^a	0.12	0.724
Impact Medical Condition ^a	0.19	0.664
Location Motor Dysfunction	0.66	0.720
Level Motor Dysfunction	0.93	0.627
Ambulatory Skills ^a	1.38	0.240
Toileting Skills	4.39	0.111
Social Behavior	2.49	0.288
Expressive Language ^a	1.46	0.228

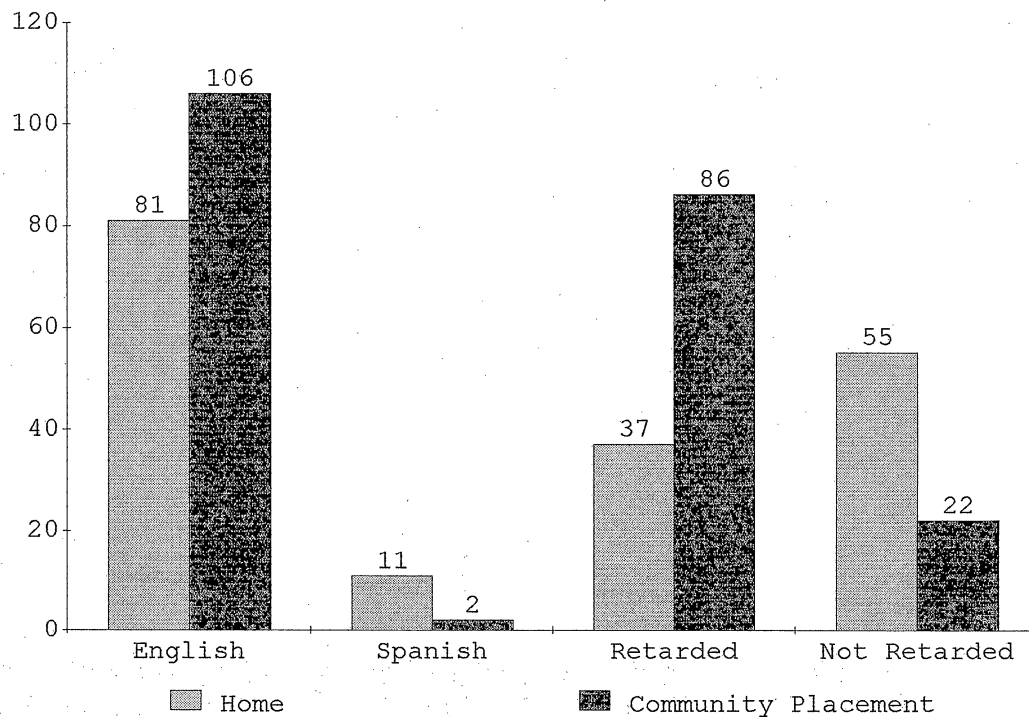
^aChi-Square is Yates corrected for this variable.

Other Relationships

Two other relationships found to be significant had to do with out-of-home placement. Not surprisingly, individuals with cerebral palsy and mental retardation are more likely to live in a board and care facility than individuals with no mental retardation, who are more likely

to live at home. It was also found that individuals with cerebral palsy who only spoke Spanish were more likely to reside in their own homes or with relatives.

Figure 1. Comparisons of Place of Residence, Primary Language and Retardation for Clients with Cerebral Palsy



A chi square table was run to check for the relationship of Spanish speaking clients and their place of residence. The data indicated that there was a significant relationship between these two variables. The Yates corrected p-value was 0.009. The majority of Spanish

speaking clients reside with their families when compared to there English speaking counterparts that tended to reside in community placement settings.

A chi square table was run to find whether there was significance between the level of retardation of a client, and their place of residence. In this table the residential variable was re-coded into two groups, living at home, or in community placement. This chi square showed significance with a Yates corrected p-value of 0.000. It indicated that the majority of individuals affected by retardation do not live at home and that the majority of those unaffected by retardation do live at home.

Chapter 5

Discussion

Conclusions

This study has taken a look at the characteristics, both physical and behavioral that could potentially be factors in the utilization of day program services for the cerebral palsied population. The purpose of this study was to explore these characteristics and factors in an attempt to better plan and develop services for clients with cerebral palsy. The clients studied are all eligible to receive services through the regional center, a state wide agency serving the needs of the developmentally disabled. The goals of the regional center are progressive with the needs of the community, and their mission is to provide appropriate resources to their clients.

This study was done in order to explore and better understand some of the areas of need of individuals with cerebral palsy. The research question studied was the following: What physical and behavioral characteristics of cerebral palsy affect procurement of appropriate day program services? The hypothesis is the existence of a relationship between the severity of affliction of the cerebral palsied client and the availability of appropriate day program services. The characteristics of cerebral palsy

of each client will keep a client from participating in a day program. The initial belief was that physical and social characteristics would be the greatest factors in day program participation. This study revealed that the problems of persons with cerebral palsy have less to do with their physical limitations, and may have more to do with their environmental circumstances such as their place of residence.

Physical characteristics did have an influence on participation in a day program. The analysis done on the data showed that there was a significant influence on day program participation when the client was more affected by mental retardation. Clients with mental retardation ranging from the moderate to severe range tended to attend day programs more often than clients with only mild or no level of mental retardation.

The same was true for clients residing in community placement versus independence or a parental home. Those individuals that resided in a community type placement were more likely to be attending a day program. It is believed that the data represents the influence of care providers in community placement, who tend to encourage their clients to participate in a day program. Even though the client has the right to refuse participation in a day program, there

seems to exist some degree of pressure to encourage clients to attend.

The majority of clients attending day programs attend those funded by the regional center and habilitation. The majority of regional center funded programs are those programs that provide services to individuals with greater disability, and less ability for independence. These clients also make up the majority of clients in community placement. There are exceptions to the rule but the data shows that more severely disabled clients reside in community placement, and the less disabled are residing independently or with family.

The family may play a factor in the use of day program services by clients as well. The data seems to indicate that, although the majority attended day programs, almost one third did not. This might be a result of parental over protectiveness. Further study in this area could more specifically address this issue.

Another factor influencing day program participation for those living at home is their lower incidence of mental retardation. Those clients residing at home were more often less retarded or not retarded at all. There may be the need to provide more appropriate services for these clients at their level of ability, rather than fitting them into programs where more severely retarded clients attend.

Programs of supported employment do exist but these programs are nowhere as numerous as the sheltered programs funded by the regional center and Habilitation.

The current trend is to move away from the sheltered program and into a client centered support system to encourage independence. The hope is of creating a community support network for the client and to reduce the concealment of disabled individuals.

The gender of the person was a significant factor which affected day program participation. Males attended day programs more often when compared to the females. There were nearly twice as many females not attending day program when compared to males. Differing social expectations may be the cause of the difference observed between males and females, as well as a tendency for families to be more protective of females than males. This could be an area of further investigation to further explore the relationship between gender and day program participation.

The primary language as well as the client's ability to express himself were also significant in the relationship to day program participation. It seems that the majority of clients attending day programs spoke or understood English. Monolingual, Spanish speaking clients were under-represented in day programs. The analysis showed that 77 percent of English speaking clients attended day programs, while only

46 percent of Spanish speaking clients were attending. Expressive language was not a significant factor to the equation. The statistics showed that the numbers of clients attending and not attending day programs were similar regardless of expressive ability.

As discussed earlier, the home environment and over-protective parents may be influencing this statistic. The chi square tables indicate that there is a significant relationship between the client residing at home and primary language. The majority of the Spanish speaking clients live at home. Less than half of the English speaking clients live at home, and are therefore less affected by parental over-protectiveness. Further research on culture and legal status and the possible influence on day program attendance is needed.

The variables expected to most influence day program participation, in fact, did not. Therefore, the null hypothesis was not rejected. These variables included social behavior, ambulatory skills, toileting skills, medical conditions and their impacts, location of the cerebral palsy motor dysfunction, as well as the level of physical limitation, and age of the client. These physical characteristics had no significant bearing on the use of existing day programs. It should be noted that the existing day programs have been developed with the developmentally

disabled in mind. The data might be different if these programs were non-existent. The data analysis showed that the variety of day program opportunities were provided by the regional center, the department of rehabilitation, and by the local school districts. There were few private sources which provide services to clients with cerebral palsy.

Recommendations and Implications for Practice

The initial expectations of this researcher were that clients with cerebral palsy were not being served adequately by existing services. In part, it was felt that the Inland Regional Center was not providing adequate resource options to clients with cerebral palsy. The data indicates that the Inland Regional Center is providing clients with options to day program services, as well as funding the majority of programs for the most disabled clients. It indicates to some degree that program development over the years has helped to fill the need of clients with cerebral palsy within the community. There seems to be a need for service provision to clients who speak a language other than English, as well as to clients residing at home. This might be as simple as educating family members to the availability

of community based resources, and to encourage them to take a worthwhile risk. Parental over-protectiveness is a result of parental investment in the child's disability (Blumberg 1975). Encouragement and support to the families could improve the opportunity of a person living at home to participate in a day program.

The literature suggests that the person with cerebral palsy is confident with his physical abilities and feels equal to other non-disabled individuals. The data suggests that mentally capable persons need appropriate day programs. The disabled person is in need of opportunities for participation and less in accommodation. The ADA will provide the disabled with the accommodation they need through federal mandate. The process of program development should continue to maintain a progressive approach in the community. Case managers should be encouraged to work with clients and their families as a system. It is through the family system that the support and encouragement will improve the chances for successful day program placements.

This study supports the need for social workers to be sensitive to clients and their families. The social worker has knowledge of available resources in the community. It is up to the social worker to provide the family with education, and encouragement, in a sensitive way that will

strengthen the worker/client relationship and will improve the client's chances of participating in a program.

The data indicates that there is discrepancy in the use of day programs based on gender. This issue should be looked at more closely, possibly in a future study, to investigate the relationship between male and female participation in day programs. As an example, the types of physical and social factors that influence day program attendance of males and females with cerebral palsy could be studied.

The administration of regional center should consider ongoing education to provide their case management staff with opportunities to strengthen their own skills. It is important, as well, to have a clear mission statement and a knowledge of the purpose of the agency in order to best represent the goals of the regional center.

Implications for Research

This study is limited by the clients and day programs which it studied. The study examined only the cerebral palsied population of the Inland Regional Center and the results cannot be generalized to fit the different circumstances of other regional centers, or community services. The framework of this study could be used to do

exploratory studies at other regional centers, or a regional center system wide study through the Department of Developmental Services. This study could be helpful in providing information on client day program needs in the community as well as throughout the state. It can help in planning and resource development for areas where client non-participation is significant.

Further studies in this area could focus on the families of clients residing at home, as well as the service providers of local day programs. This study was limited by the data that it examined. Although the CDER data is rich in information, it fails to take into account the attitudes of families and service providers. A study to assess these attitudes would help to clarify the situations of cerebral palsied clients seeking services in the community.

This study was exploratory in nature and served to provide some avenues for further research. It also provided data that indicates a need for further program development and social worker education. Its implications to research are simple. It provided a great deal of information through a straight forward research design using existing data. The use of existing data such as this should be encouraged in future studies. Such data can be enriched, as well, through follow up interviews with family members and/or clients.

Appendix A
Data Abstraction Form

Appendix A

Data Abstraction Form

Subject ID# _____

Variable:

Gender M F

Age _____

Ethnicity 0-Mixed 1-Asian 2-Afr-Amer
 3-Filip 4-Nativ-Amer 5-Polynes
_____ 6-Hispanic 7-Caucasion 8-Other
 9-Unknown

Primary Language 11-English 24-Spanish 31-Canton
32-Mandarin 33-Japanese 34-Vietnamese 99-None

Expressive Language 1-Makes no sound 2-Babbles No Words
3-Says simple words 4-Says two words 5-Sentences 3+ words
6-Basic conversation 7-Complex conversation

Ambulatory Skills 1-Does Not Walk 2-Walks with support
 3-Walks alone unst 4-Walks alone well

Toilet Skills 1-Not toilet trained 2-Habit trained
 3-Indicates need 4-Toilets w/assist
 5-Completes by self

Lvl of Motor Dysfunc. 1-Mild 2-Moderate 3-Severe
 4-CP suspected

Location of Motor Dysfunc. 1-Monoplegia 2-Hemiplegia
 3-Diplegia 4-Triplegia
 5-Paraplegia 6-Quadraplegia
 7-Other

Retardation Level 000.0-No Retard 317-Mild
 318.0-Moderate 318.1-Severe
 318.2-Profound 319-MR Suspected

Medical Conditions # _____

Medical Conditions 0-No evidence 1-Mild 2-Moderate
Impact 3-Severe 9-Cond. susp. undeterm.

Day Program 0-None 1-NP, Cl refuses 2-NP, Severe Beh
 3-NP, Med Fragile 4-NP, No trans 5-Pub schl
 6-Dept of Rehab 7-Reg Ctr Fund 8-Oth Pub Fn
 9-Other priv fund X-N/A

Social Behavior 1-Unacceptable 2-Disrupt social part.
3-Seldom interferes 4-Do not occur

Residence Type Codes 11-99 Available through CDER
Manual Type: _____

References

- Alexander, M. (1990). Cerebral palsy. Psychological aspects of developmental and physical disabilities: A casebook.; Michael Herson, Vincent B. Van Hasselt, Eds. Sage Publications, Inc., Newbury Park, CA, US. p. 87-93.
- Barney, O. (1974). Client age, education, and work experience as predictors of rehabilitation outcome. Vocational Evaluation & Work Adjustment Bulletin, v7 (n1):25-30.
- Basil, C. (1992). Social interaction and learned helplessness in severely disabled children. AAC: Augmentation & Alternative Communication, v8 (n3):188-199.
- Blumberg, M. L. (1975). Psychodynamics of the Young Handicapped Person. American Journal of Psychotherapy, 29, (4), 466-76.
- California. Department of Developmental Services. State of California health and Welfare Agency. 1986a. Client developmental evaluation report manual. Sacramento, CA: Author.
- California. Department of Developmental Services. State of California Health and Welfare Agency. 1990. Long range plan 1990-1995. Sacramento, CA: Author.
- Funk & Wagnalls (1986). Funk & Wagnalls New Encyclopedia, Vol. 8, pp. 311-312. USA: R. R. Donnelly & Sons Company.
- Fox, V. M. (1984). Pilot Study of Novel Test Instrumentation to Evaluate Therapeutic Horseback Riding. Adapted Physical Activity Quarterly, v1 (n1): 30-36.
- Janicki, M. (1982). The Character of Developmental Disabilities in New York State: Preliminary Observations. International Journal of Rehabilitation Research, v5 (n2):191-202.
- Jonas, J. (1981). Cerebral palsy: Yesterday, today, and tomorrow. Annual Review of Rehabilitation, v2: 192-211.

- Knishkowsky, B.; Gross, M.; Morris, S.; Reeb, K.; and others. (1986) Independent living: Caring for the adult with Cerebral palsy. Journal of Family Practice, v23 (n1):21-27.
- Lubin, R.; Jacobson, J.; and Kiely, M. (1982). Projected impact of the functional definition of developmental disabilities; The categorically disabled population and service eligibility. American Journal of Mental Deficiency, v87 (n1):73-79.
- McDonald, E. (1973). Communication Boards for Cerebral Palsied Children. Journal of Speech and Hearing Disorders, v38 (n1):73-88.
- Magill-Evans, J. (1991). Self-Esteem of Persons with Cerebral Palsy: From Adolescence to Adulthood. American Journal of Occupational Therapy, v45 (n9):819-825.
- Mason, M. (1989). Effects of a Therapeutic Horseback Riding Program on self-concept in adults with cerebral palsy. Dissertation Abstracts International, v49 (n9-A): 2590-2591.
- Orlin, M. (1995). The Americans with Disabilities Act: Implications for Social Services. Social Work v40, (n2):233-239.
- Romanova, O. L. (1983). An Experimental Psychological Study of the Personality Traits of Patients with Physical Defects. Soviet Neurology & Psychiatry, v16 (n1):29-36.
- Stelk, W.; Richards, J. (1992). Individualized residential services for persons with developmental disabilities. Community Alternatives: International Journal of Family Care, v4 (n2):201-220.